3044 words

Disclosure of adverse events: A data linkage study reporting patients' experiences amongst Australian adults aged 45 and over

Background: Since Australia initiated national Open Disclosure Standards in 2002 open disclosure policies have been adopted in all Australian states and territories. Yet, research evidence regarding its adoption is limited. This study aimed to determine the frequency with which patients who report an adverse event had information disclosed to them about the incident, including whether they participated in a formal open disclosure process, their experiences of the process and the extent to which these align with the current NSW policy.

Methods: A cross-sectional survey about patient experiences of disclosure associated with an adverse event was administered to a random sample of 20,000 participants in the 45 and Up Study who were hospitalised in New South Wales (NSW) Australia between January and June 2014 .

Results: Of the 18,993 eligible potential participants, 7,661 surveys were completed (40% response rate) with 474 (7%) patients reporting an adverse event. Of those who reported an adverse event, a significant majority reported an informal/bed-side disclosure (91%, 430/474) with only 79 (17%) of patients participating in a formal open disclosure meeting. The majority of informal disclosures were provided by nurses with only 25 percent provided by medical practitioners.

Conclusions: Most patients suffering an adverse event were told about the incident informally, including over half the patients who experienced a moderate to severe event; the guidelines require these patients to be offered formal open disclosure. Experiences of open disclosure may be enhanced by informing patients of their right

to full disclosure in advance of or on their admission to hospital, and recognition of and support for informal/bed-side disclosure for appropriate types of incidents. A review of the open disclosure guidelines in relation to the types of adverse events that require formal open disclosure and those events more suitable to informal bed-side disclosure is indicated. Guidelines for bed-side disclosure should be drafted to assist medical practitioners and other health professionals facilitate and improve their communications about adverse events. Alignment of formal disclosure with policy requirements may also be enhanced by training multidisciplinary teams in the process.

Keywords: incident disclosure; open disclosure; adverse events; medical error; ethics; patient experience; patient satisfaction

Background

Honest communication with patients, an enduring ethical tenet, today includes additional disclosure obligations for iatrogenic injuries. The strong evidence of system-related harm to patients gathered over the last two decades underpins the specific guidance to health professionals to be open and honest about what happened, why and what will be done to address the problem.[1] This principle of being honest with patients after a health care incident underpins open disclosure.[2] Open disclosure is defined as 'an open discussion with a patient about an incident(s) that resulted in harm to that patient while receiving health care.'[3]

In 2008, The National Open Disclosure Standard was published by the Australian Commission on Safety and Quality in Healthcare.[3,4] The Standard required healthcare organisations to provide an expression of regret, an explanation of what happened, and a description of the action being taken to manage the incident and

prevent reoccurrence.[4] Formal open disclosure involves an exchange of information that may take place over one or several meetings.[3, 5-8] Each jurisdiction has published open disclosure guidelines whose principles align with the National Standard. The requirements of the New South Wales (NSW) open disclosure policy are shown in Box 1.

<INSERT BOX 1>

Most open disclosure policies concern adverse events that have either the potential for, or have caused actual, patient harm.[8-10]. A 2012 review of the Australian Open Disclosure Standard found many patients were dissatisfied with open disclosure because of the lack of timeliness, openness and transparency.[4] Similarly, a national study of the UK open disclosure policy guidance 'Being Open' revealed tension between the principles documented and the reality in practice.[10]

A 2014 literature review showed disclosure to be a significant topic of debate. The few primary research studies of patients' experiences of open disclosure processes[10-14] consistently found that open disclosure did not meet patient expectations. In Australia, the 100 Patient Stories project found that while patients welcomed open disclosure, they were not adequately followed up with tangible support or information about changes in practice, not being offered an apology, and not having the opportunity to meet with staff directly involved in the event.[11]

Studies of disclosure have previously relied upon hypothetical rather than real-life experiences or included small patient samples.[10,17] A recognised research barrier is

contacting patients who have suffered adverse events, mainly due to medico-legal and confidentiality restrictions.[15,16] Patient samples identified through health services, internet research companies or by advertising in national print media are limited by the potential to generate a biased sample of patients with particularly positive or negative experiences.[11,18] Patients may also not be aware that an adverse event occurred and therefore not volunteer.

Using data linkage, we identified a large cohort of recently hospitalised patients to survey regarding their experiences in NSW hospitals in an attempt to reduce the biases noted above.[19] Respondents who reported an adverse event were asked questions about how they were informed about it. Our study aimed to determine the frequency with which patients (who experienced an adverse event) were engaged in a formal open disclosure process, their experiences and the extent to which these align with the NSW Open Disclosure Policy (Box 1).

Methods

The methods are reported in brief as they are detailed elsewhere. [reference removed for blinding]

Ethics approval

The conduct of the 45 and Up Study was approved by the NSW Population and Health Services Research Ethics Committee. The patients' experience study received additional ethics approval from this committee.

Design

This is a mixed methods study involving data collection via cross-sectional survey and data linkage between The Centre for Health Record Linkage (CHeReL), the Admitted Patient Data Collection (APDC), the Register of Births, Deaths and Marriages (RBDM) and the 45 and Up Study databases.

Setting and participants

The study utilised the Sax Institute's 45 and Up Study cohort of older adults in Australia which includes a database of 267,153 citizens aged 45 and over. Prospective 45 and Up participants were randomly sampled from the Department of Human Services (formerly Medicare Australia) enrolment database, which provides near complete coverage of the population. People aged 80 and over and residents of rural and remote areas were oversampled. Those agreeing to participate completed a baseline questionnaire (between Jan 2006 and December 2009) and consented for follow-up and linkage of their information to routine health databases. Evidence suggests that the 45 and Up population gives results which are consistent with other population-based health-related studies in NSW.[20,21] Respondents in this study were randomly selected from a sample of 20,000 individuals from the 45 and Up cohort who were hospitalised in NSW between January and June 2014. The group, who provided additional consent to take part in this sub-study, were identified using data linkage via the Centre for Health Record Linkage (CHeReL) with the Admitted Patient Data Collection (APDC) administered by NSW Health. This dataset captures patients in public district and tertiary hospitals, and private hospitals.

Survey tool

A five-part survey was administered to patients. This paper analyses part four of the survey which captured patients' communications with health professionals after an adverse event.[22] To assist patients complete the survey we provided them with the following key terms (see Box 2).

INSERT BOX 2

Analysis

Frequencies and percentages were calculated using Stata IC- (Stata Statistical Software: Release 13 College Station, TX: StataCorp LP). Pearson Chi squared tests were used to assess differences between those who did and did not receive formal open disclosure. A significance level of 0.05 was used for analyses. Free-text data were managed using NVivo 10.[23] Two researchers read separately the free-text responses and identified key themes. Researcher discussions identified groups of themes which were merged into categories and labelled. A third researcher rechecked the categories and themes.

Results

Preliminary analysis

There were no differences between responders and non-responders in age (distribution for non-responders was the same as responders; p=0.95), gender (49% of non-responders were male; p=0.49), English as their main language (92% of non-responders; p = 0.63), local government area (distribution for non-responders was within 1% of responders in each category; p=0.84) or level of education (distribution for non-responders was the same as responders; p=0.93).

Of the 20,000 potential respondents from the 45 and Up study who were invited to participate, 18,993 were eligible. Completed surveys were received from 7661 (40% response rate). Potential respondents were ineligible if the postal survey was returned to sender (640), reported as deceased (189), or they responded to say the data linkage was not correct and that they had not been in hospital (178).

Of the 7661 respondents, 474 reported experiencing an adverse event (7%). Table 1 provides the demographic breakdown of the sample of respondents who reported an adverse event.

<INSERT TABLE 1>

Table 2 identifies the position of the health professional who told the patients about the incident regardless of whether this was via a formal or informal disclosure. Of those who reported an adverse event, a significant majority reported an informal/bed-side disclosure (91%, 430/474) with only 79 (17%) of patients participating in a formal open disclosure meeting(s). Just under half of the informal disclosures were provided by nurses (205/48%), followed by medical practitioners (109/25%) and then a multi-disciplinary team (17%).

<INSERT TABLE 2>

Of the 474 respondents who experienced an AE, 428/474 (90%) had at least one formal open disclosure meeting (Table 3). Of this group, 79/428 respondents (18%)

had at least one formal open disclosure meeting and 349/428 (82%) reported no meetings. For those who experienced an AE, being female (22% v 15%, p = 0.05), severity of the event (24% v 16% , p=0.04) and a weekend admission (25% v 16%) were all more likely to have a formal open disclosure meeting (see Table 3). No significant differences were identified in age (p=0.35), admission status (p=0.30), language other than English (p=0.30), education level (p=0.06), or local health district (p=0.48).

<INSERT TABLE 3>

Table 4 summarises the feelings of those who experienced an AE and whether or not they had an OD meeting. Patients participating in a formal OD meeting were less likely to be angry (33% v 56%; p<0.001), were more likely to be confident they were in good hands (68% v 48%; p=0.002), were more satisfied with how they were treated (63% v 47%; p=0.015), and more likely to feel that doctors/nurses were open and honest (68% v 48%; p=0.001).

<INSERT TABLE 4>

Table 5 summarises comments from respondents who were offered formal open disclosure. The questions reflect the steps that are outlined in the NSW Health Open Disclosure Policy and the responses from patients indicate whether they had experienced the activity.[7] Those who said the question was not applicable to their situation were removed from the analysis and the numbers of valid responses for each item shown.

<INSERT TABLE 5>

For those having at least one formal open disclosure meeting, the meeting occurred within 48 hours of the incident in 60% of cases. About half of those (who had at least one formal open disclosure meeting) had an experience that complied with the Policy:- being given the name of a hospital contact to liaise with (23/49 =47%); being offered the opportunity to have a support person present (21/48 = 44%) and being given an apology or expression of regret (23/53 = 43%). The majority were provided with an explanation about the incident (46/62 = 74%), asked questions (54/60 = 90%) and given clear information about the consequences of the incident (39/58 = 67%). Almost half (19/40%) had no information as to how similar events would be prevented in the future. Few were given options about the staff who would be attending the open disclosure meeting (9/44 = 20%) or were provided with written information about what was discussed (5/41 = 12%).

Qualitative findings

Positive aspects of open disclosure meetings identified by respondents fell into three categories: a human approach; openness and honesty; and reciprocal discussion and resolution.

A human approach describes the impact of staff who were caring, friendly, helpful and good listeners on patients' experiences. This approach is evidenced in the following quotations:

> *'The hospital representative was honest and caring. She made my husband, daughter and myself welcome and was a good listener.'*

Openness and honesty with patients about adverse events are central to any disclosure process. Participants expressed a positive experience of disclosure when discussions were genuine and frank, with staff taking the time to address their questions and concerns. This is represented in the following comments:

> *'Questions were answered frankly & openly.'*
>
> *'They came to the point and there was no attempt to down play the incident.'*

Positive experiences were also associated with disclosures that were consultative and with clear explanations about what happened. Respondents were satisfied when they understood what had happened to them but also when they had a mutually agreed resolution to the event.

'Their explanations and assistance and treatment were clear and helpful.'

'The openness of the information given and the treatment recommended.'

Negative experiences of open disclosure were also identified, with three categories emerging: lack of an open disclosure process; inadequate implementation of open disclosure; and non-responsive staff.

The *lack of an open disclosure process* was a key feature of negative patient responses, with many reporting open disclosure was either not offered or involved one meeting that was insufficient.

'I was never offered open disclosure.'

'There were no meetings only my follow up visit with [my doctor] who abused me for writing a letter of complaint.'

Some respondents found the open disclosure process inadequate reporting lack of privacy for discussions, unsuitable staff attending the meetings, lack of opportunity to have a support person, unplanned meetings without time for preparation and lack of written confirmation of the discussions. These factors contributed to a poor patient experience of the process, as exemplified in these quotations:

'[open disclosure should have been] given privately and not in front of patients in 4 bed ward.'

'I would prefer someone higher up would have been present and a copy of the report given to me.'

Respondents also identified negative experiences involving staff who failed to attend to their concerns or feelings during open disclosure, did not to listen to them, did not use clear language and were patronising and/or uncaring.

'The doctor and nurse were verbally angry with each other, ignored me.'

'We were patronised, lied to, treated with arrogance & disrespect.'

Respondents suggested staff listening and attending to patient concerns would improve the experience. Notably, although only two patients discussed the need for an apology or the desire for compensation; the overall focus of comments was on the importance of having the opportunity to have open disclosure meetings and the approach taken by staff to these meetings.

Discussion

This study provides new knowledge about disclosure after an adverse event among a large cohort of recently hospitalised patients. Most respondents, who were aware of their adverse event, were informally told of the event by doctors and nurses. Most practitioners would be aware of their ethical obligation to disclose an adverse event to their patient but may fear that disclosure according to the guidelines exposes them to more than just the patient's response to the event.[8] This ethical obligation refocuses practitioners to long standing traditions that underpin trust in the doctor-patient relationship - the duty of candour.[1,24] The results of this study indicate that

'informal' bed-side disclosure may be an area for further exploration. More than half the patients experiencing an adverse event rated the incident as moderate to severe. NSW Health requires an open disclosure process for serious adverse events; yet, nearly half of those who reported adverse events with moderate to serious effects were told about the event informally. Further research is required to better understand why there is a preference for informal disclosure even when an adverse event is moderate or serious and to explore the implications of increasing emphasis on multidisciplinary team in the disclosure of adverse events.[25]

Open Disclosure is a prominent policy leaver and comprehensively promoted in Australia. The evidence demonstrates disclosure is the ethical and appropriate course of action following an adverse healthcare event.[3,8,10,26] Our study showed that only a small proportion of respondents engaged in a formal open disclosure process. While there is evidence in research and policy literature of the value of formal open disclosure processes, our data suggests implementation across the health system remains a problem, despite extensive training during its introduction in NSW. Challenges include introducing policies in large scale organisations; matching patient expectations with practice; reconciling legal privilege associated with quality improvement initiatives and open disclosure requirements; understanding of open disclosure and liability compensation; and how to measure disclosure.[26] Uncertainty about what and how to disclose has been identified in the research literature as a further barrier.[27]

Informal disclosure occurs when information about an adverse event is shared with a patient- usually at the bedside - and outside of the policy framework. There is usually

no prior planning leaving the patient unprepared for a meaningful and detailed discussion about what happened to them. Informal open disclosure, particularly for serious incidents, may fulfil an ethical duty to disclose harm, but is less transparent and may leave patients with incomplete information about their wellbeing and future care. Our results show that health professionals are committed to disclosure and engage in discussions with patients and carers but shire away from utilising the open disclosure guidelines, even when there are clear guidelines that they should. One explanation is the different appreciation by staff of what constitutes a 'moderate' or 'serious' event and thus whether formal open disclosure was required. In other cases, staff may not have recognised the patient's experience as an adverse event. The results confirm staff attention to their duty of candour and may satisfy patients suffering less serious adverse events. The challenge is to ensure that when a patient suffers a serious adverse event they are supported by health professionals who are familiar and experienced in providing open disclosure that conforms with the national standard.

When open disclosure was implemented patients in our study reported the quality of the process as variable. [11,12] Patients identified the lack of opportunity to decide who should attend open disclosure meetings- a finding reflected in The 100 Patient Stories project.[11] Patients understandably want the clinicians directly involved in the event to attend the meeting, along with the patient's support person; a position supported by the Medical Board's Code of Conduct requirements.[11] The manner in which patients were addressed was another concern with patients left feeling patronised, rushed and ignored by hospital staff. Respectful treatment of patients, the

touchstone of patient-centred care, transcends all areas of health service provision.[24,28]

Limitations

A potential limitation of our study is that our sample is from the 45 and Up Study, which may or may not be generalizable to all NSW hospital patients. For example, while only 25% of the 45 and Up Study were born outside of Australia, 2011 census data puts this figure at 39% for those aged 45 and over in NSW.[20,21] Given that we studied patient experiences of the NSW Open Disclosure policy, the extent to which we can generalise our findings outside of the NSW context is limited; although similar policies exist nationally and internationally.[10] We did not survey the experiences of some important groups - patients who died, patients who lacked the capacity to consent and family members or carers of hospitalised patients. Lack of data from family and carers is particularly important in the context of open disclosure.

Conclusion

The results of this cross-sectional study show patients are having discussions about their adverse events with health professionals, but mainly informally and therefore outside the recommended formal open disclosure guidelines. Experiences of open disclosure may be enhanced by informing patients of their right to full disclosure in advance of or on their admission to hospital. Recognition of and support for informal/bed-side disclosure for appropriate types of incidents may also enhance patients' experiences. A review of the open disclosure guidelines in relation to the types of adverse events that require formal open disclosure and those events more suitable to informal bed-side disclosure is indicated. Guidelines for bed-side

disclosure should be drafted to assist medical practitioners and other health professionals facilitate and improve their communications about adverse events. Alignment of formal disclosure with policy requirements may also be enhanced by training multidisciplinary teams in the process.

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References

1. Medical Board of Australia. Good medical practice: a code of conduct for doctors in Australia, 2014. Available at: http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx [accessed 16 February 2017]
2. Kraman S, Hamm G. Risk Management: extreme honesty may be the best policy. Ann Intern Med. 1999;131(12):963-7.

3. Australian Commission on Safety and Quality. Open Disclosure Standard Review Report, 2012. Sydney: Australian Commission on Safety and Quality; 2012 Available from: http://www.safetyandquality.gov.au/publications/open-disclosure-standard-review-report/ [accessed 16 February 2017]
4. Australian Commission on Safety and Quality in Health Care. Open Disclosure Standard Review Report. ACSQHC, Sydney 2012.
5. Wu A, McCay L, Levinson W, et al. Disclosing adverse events to patients: International Norms and Trends. Journal of Patient Safety 2017; 13(1): 43-49.
6. NHS Serious Incident Framework, 2015; https://www.england.nhs.uk/patientsafety/wp-content/uploads/sites/32/2015/04/serious-incidnt-framwrk-upd2.pdf [accessed 16 February 2017]
7. Canadian Patient Safety Institute. Canadian Disclosure Guidelines. Being Open with Patients and Families. 2011. URL: www.patientsafetyinstitute.ca/English/toolsResources/disclosure/Documents/CPSI%20Canadian%20Disclosure%20Guidelines.pdf [accessed 16 February 2017]
8. NSW Health 2014. Open Disclosure Policy. Available at: http://www0.health.nsw.gov.au/policies/pd/2014/pdf/PD2014_028.pdf [accessed 16 February 2017]
9. Birks Y, Entwistle V, Harrison R, Bosanquet K, Watt I, Iedema R. Being open about unanticipated problems in health care: the challenges of uncertainties. Journal of Health Services Research & Policy 2015; 20(1 suppl): 54-60.
10. Birks Y, Harrison R, Bosanquet K, Hall J, Harden M, Entwistle V, Watt I, Walsh P, Ronaldson S, Roberts D, Adamson J, Wright J, Iedema R. (2014).

An exploration of the implementation of open disclosure of adverse events in the UK: a scoping review and qualitative exploration. Health Services Delivery and Research, 2(20).

11. Iedema R, Allen S, Britton K, et al. Patients' and family members' views on how clinicians enact and how they should enact incident disclosure: the "100 patient stories" qualitative study. British Medical Journal. 2011; 343:d4423.
12. Mazor KM Roblin DW Greene SM et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. J Clin Oncol 2012;30:1784–90.
13. Hobgood C, Tamayo-Sarver JH, A, et al. Parental preferences for error disclosure, reporting, and legal action after medical error in the care of their children, Pediatrics 2005; 116: 1276-86.
14. Kooienga S Stewart VT. Putting a face on medical errors: a patient perspective. J Healthcare Qual 2011; 33:37–41.
15. Iedema R, Allen S, Sorensen R, Gallagher TH. What prevents incident disclosure, and what can be done to promote it? The Joint Commission Journal on Quality and Patient Safety 2011; 37(9): 409-417.
16. Studdert DM, Mello MM, Gawande AA, Brennan TA, Wang YC. Disclosure of medical injury to patients: an improbable risk management strategy. Health Affairs 2007; 26:215-6.
17. Gallagher TH, Waterman AD, Ebers AG, Fraser VJ, Levinson W. Choosing your words carefully: how physicians would disclose harmful medical errors to patients. Arch Intern Med 2006; 166:1585-93.

18. Harrison R, Walton M, Manias E, et al. The missing evidence: a systematic review of patients' experiences of adverse events in health care. International Journal of Quality in Health Care. 2015; 27(6):424-42
19. Walton M, Smith-Merry J, Harrison R, et al. Using patients' experiences of adverse events to improve health service delivery and practice: protocol of a data linkage study of Australian adults age 45 and above. BMJ Open. 2014;4(10): e006599.
20. 45 and Up Study Collaborators, et al: Cohort profile: the 45 and Up Study. Int J Epidemiol 2007, 37(5):941-7.
21. Mealing NM, Banks E, Jorm LR, Steel DG, Clements MS, Rogers KD. Investigation of relative risk estimates from studies of the same population with contrasting response rates and designs. BMC Med Res Methodol. 2010; 10:26.
22. Iedema R, Sorensen R, Manias E, et al: Patients' and family members' experiences of open disclosure following Adverse Events. Intl J Qual Health Care 2008, 20(1):421-32.
23. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006 Jan 1;3(2):77-101.
24. General Medical Council. Openness and honesty when things go wrong: the professional duty of candour 2015. http://www.gmc-uk.org/guidance/ethical_guidance/27233.asp [accessed 26 September 2016]
25. Harrison R, Birks Y, Bosanquet K, Hall J, Iedema, R. The contribution of nurses to incident disclosure: A narrative review. International Journal of Nursing Studies 2013; 51(2): 334-345.

26. Wu A, McCay L, Levinson W, et al. Disclosing Adverse Events to Patients: International Norms and Trends. J Patient Saf 2017;13: 43–49.
27. Harrison R, Birks Y, Iedema R, Bosanquet K. Enacting open disclosure in the UK National Health Service: a qualitative exploration. Journal of Evaluation in Clinical Practice 2017 (epub online first).
28. Clinical Excellence Commission. Open Disclosure. Available at: http://www.cec.health.nsw.gov.au/incident-management/open-disclosure [accessed 16 February 2017]
29. Australian Bureau of Statistics. State and territory composition of country of birth, 2011. Available at: http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/3412.0Main%20Features42014-15?opendocument&tabname=Summary&prodno=3412.0&issue=2014-15&num=&view= [retrieved 21 march 2017]

Table 1 Demographics of respondents who reported having an adverse event

Variable	N	%
Sex (n=474)		
Male	226	48
Female	248	52
Age group (n=473)		
50-59	73	9
60-69	142	30
70-79	142	30
80-110	116	25
Non-English language spoken at home (n=474)		
Yes	44	9
No	430	91
Highest qualification (n=468)		
No school certificate	78	17
School or intermediate	105	22
Higher school	45	10
Trade or apprenticeship	54	12
Certificate or diploma	100	21
University degree	86	18
Hospital type (n=474)		
Public	246	52
Private	228	48
Admission status (n=472)		
Emergency	152	32
Non-emergency/planned	320	68

Local health district (n=418)		
Central Coast	20	5
Illawarra Shoalhaven	25	6
Nepean Blue Mountains	20	5
Northern Sydney	45	11
South Eastern Sydney	53	13
South Western Sydney	37	9
Sydney	13	3
Western Sydney	20	5
Far West	1	<1
Hunter New England	66	16
Mid North Coast	23	6
Murrumbidgee	28	7
Northern NSW	33	8
Southern NSW	14	3
Western NSW	20	5
Severity of adverse event (n=447)		
No or mild effects	175	39
Moderate or severe effects	272	61
When the adverse event occurred (n=439)		
Weekday	382	87
Weekend	57	13

Table 2 Frequencies of sources of advice that an incident had occurred

Who advised patient of the incident (n=430)	**Frequency (%)**
Nurse	205 (48)
Multi-professional team	72 (17)
Consultant	68 (16)
Other (not specified)	42(10)
Registrar	26 (6)
Intern	10 (2)
Medical student	5 (1)
Nursing student	2 (<1)

Table 3 Feelings reported by patients after advised of a healthcare incident

Feeling	**Agree (%)**	**Neutral (%)**	**Disagree (%)**
Angry (n=417)	216 (52)	73 (18)	128 (31)
Relieved to know (n=398)	221 (56)	84 (21)	93 (23)
Depressed (n=417)	182 (44)	95 (23)	140 (34)
Confident in good hands (n=418)	218 (52)	70 (17)	130 (31)
Satisfied with treatment (n=421)	213 (51)	60 (14)	148 (35)
Staff were open and honest (n=447)	233 (52)	95 (21)	119 (27)

Table 4 Characteristics of those who did and did not have at least one formal open disclosure meeting

Variable	Formal OD (N)	Formal OD (%)	No formal OD (N)	No formal OD (%)	Total (N)	Total (%)	P
Sex (n=428)							**0.05**
Male	30	15	175	85	205	100	
Female	49	22	174	78	223	100	
Age group (n=427)							0.35
50-59	16	26	45	74	61	100	
60-69	22	19	93	81	115	100	
70-79	22	16	115	84	137	100	
80-110	19	17	96	83	115	100	
Non-English language (n=428)							0.30
Yes	10	24	31	76	41	100	
No	69	18	318	82	387	100	
Highest qualification (n=422)							0.06

No school certificate	17	24	53	76	70	100	
School or intermediate	9	10	85	90	94	100	
Higher school	11	25	33	75	44	100	
Trade or apprenticeship	11	22	38	78	49	100	
Certificate or diploma	19	22	69	78	88	100	
University degree	10	13	67	87	77	100	
Admission status (n=399)							0.30
Emergency	25	17	122	83	147	100	
Planned procedure	48	19	204	81	252	100	
Local health district (n=381)							0.48
Central Coast	4	20	16	80	20	100	
Illawarra Shoalhaven	4	17	19	83	23	100	
Nepean Blue Mountains	5	26	14	74	19	100	
Northern Sydney	8	20	33	80	41	100	
South Eastern Sydney	7	14	42	86	49	100	

South Western Sydney	6	18	27	82	33	100	
Sydney	3	25	9	75	12	100	
Western Sydney	3	18	14	82	17	100	
Far West	1	100	0	0	1	100	
Hunter New England	4	7	55	93	59	100	
Mid North Coast	5	23	17	77	22	100	
Murrumbidgee	7	27	19	73	26	100	
Northern NSW	6	21	22	79	28	100	
Southern NSW	2	14	12	86	14	100	
Western NSW	3	18	14	82	17	100	
Severity of event (n=412)							**0.00**
No or mild effects	26	16	132	84	158	100	
Moderate or severe effects	50	20	204	80	254	100	
When adverse event occurred (n=404)							**0.04**
Weekday	57	16	293	84	350	100	

Weekend	15	28	39	72	54	100	

Table 5 Patient accounts of their open disclosure process

Statement	Agree (%)	Neutral (%)	Disagree (%)
I was given the name of an ongoing hospital staff contact (n=49)	23 (47)	11 (22)	15 (31)
I was given options about the time and place for OD meeting/s (n=47)	16 (34)	13 (28)	18 (38)
I was given options of which staff would attend OD meeting/s (n=44)	9 (20)	10 (23)	25 (57)
I was able to have a non-hospital support person present (n=48)	21 (44)	9 (19)	18 (38)
I was given an apology or expression of regret including ‘sorry' (n=53)	23 (43)	9 (17)	21 (40)
I was given an explanation about the incident (n=62)	46 (74)	4 (6)	12 (19)
I had an opportunity to ask questions about the incident (n=60)	54 (90)	2 (3)	4 (7)
I was given clear information on the consequences of the incident (n=58)	39 (67)	3 (5)	16 (28)
I was given the opportunity to contribute to the investigation (n=48)	18 (38)	15 (31)	15 (31)
I was told about how similar incidents would be prevented (n=46)	15 (33)	12 (26)	19 (41)
I was given a written account of the OD meeting/s (n=41)	5 (12)	9 (22)	27 (66)
Hospital staff involved in my care acknowledged the incident (n=60)	49 (82)	6 (10)	5 (8)
I was offered appropriate support to deal with the incident (n=55)	36 (65)	12 (22)	7(13)
I was given the option of arranging additional OD meetings (n=49)	18 (37)	16 (33)	15 (31)

The conclusion of the OD process was mutually agreed with me (n=49)	28 (57)	15 (31)	6 (12)